BLIND CHILDREN WITH DEVELOPMENTAL PROBLEMS

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TODAY there are approximately 35,000 children and young people under 21 years of age in this country who are blind. Although the incidence of blindness in infancy has been sharply reduced since the relationship of retrolental fibroplasia to an oversupply of oxygen in the care of premature babies was demonstrated in 1953 and 1954, the children who suffered this condition are still with us, as are children whose blindness comes from congenital or other causes. Many of these children are growing and developing well, and are already engaged in educational programs or are about to enter school. There are, however, some children who have been blind since infancy, who are presenting grave problems to their parents and to professional persons interested in providing them with appropriate educational and social services.

The blind children who are presenting these difficulties may be said to be "multiply handicapped"; but their additional handicaps are of an intangible behavioral nature rather than an obvious physical disability such as a hearing loss or a crippling condition. When seen in physicians' offices, diagnostic centers, child guidance clinics, and speech centers they are variously described as being "autistic," "mentally deficient," "psychotic," "aphasic," "emotionally disturbed" and/or "brain damaged." Many of them have been denied admission to or have been dismissed from educational programs as being too immature, not fitting into the school, uneducable, unable to talk, or in need of more individual attention.

The meager professional literature about this type of child describes an easily recognized picture of a child often frail in appearance, lacking in muscle tone, and seemingly a victim of overprotection, understimulation, and overexpectation. The one characteristic common to all such children is their developmental retardation. In the preschool years the child may be slow in responding to the efforts of his parents to teach him self-help skills such as feeding, dressing, and toileting. Often a parent will report that he is sure the child comprehends but seems almost to be teasing the adult by not wanting to cooperate.

Another frequently observed characteristic is the child's lack of language for purposes of communication. Some nonverbal children are reported as having talked at one time, perhaps in the early preschool period, and as then having gradually stopped. Others may verbalize readily or repeat in an echolalic fashion much of what they hear: abrupt phrases, television commercials, and the like. Some children speak only in the third person, never using the pronoun "I." Others do not make any attempt to communicate verbally.

This lack of communication seems to supplement the autistic or withdrawing qualities often observed. A child may appear to be indifferent to persons in his environment by simply remaining passive and initiating little activity. On the other hand, he may slowly comply with the suggestion of an adult but exhibit no change or affect. A child may show little or no preference among adults; for example, he may take the hand of a stranger as readily as that of his parent, giving little impression of discrimination between persons.

This pose of unawareness or indifference to people is most pronounced when children with similar problems are brought together in a group situation. They may be alert to the presence of each other and at times disturbed even to the point of being jealous of attention, yet they do not necessarily communicate with one another.

In gross mobility, the child often seems extremely awkward, with apparently aimless movements of arms and legs. In contrast, finer motor coordination or dexterity may be well developed. Some children may exhibit a tenseness suggestive of a spastic condition; many of the blind have been at some time or another described as "slightly palsied." Toe walking is sometimes seen as well as a toeing outward and a stiff almost stamping tread.

Many of these children exhibit behavior patterns such as head banging, rocking, face slapping, and biting. An unusual rote memory has been noted often as well as a high capacity for recall as measured by psychological instruments. These rhythmic patterns plus the ability to recall tend to enhance the child's enjoyment of music, a characteristic often capitalized upon by the adults in their lives.

These children confront the professional worker with three major questions:

1. How may this blind child's potentialities be adequately appraised or evaluated?
2. What may be contributing factors to the child's present development and is it possible to modify his retardation?
3. What kinds of services—educational, social, and psychological—are necessary to help him develop to his optimum potential?

Appraisal

Most of the children presenting problems in addition to their blindness come to the attention of the professional worker as they approach school age. Though the child might have seemed to be retarded in development earlier in his preschool years, there was always the possibility that given enough time to grow and develop he would "catch up" with his peers by the time he should be entering school.

Many schools require a psychological examination of the child before or shortly after his enrollment, particularly if he has a physical handicap. In some instances the test score will determine the child's acceptance in the program. In others, it may be used only as one of the tools of measuring his development. Authorities in child development often regard children who are blind as presenting a difficult challenge as far as appropriate evaluation is concerned especially in the preschool years. Not only are the instruments of measurement considered inadequate, but the children themselves are apt to be deceptive in appearance and their performance to belie their true potential. Yet an evaluation should be helpful to those who will be planning for and working with the child.

Much variation has been observed in the appraisal process. Some children are evaluated on the basis of one appointment with the psychologist, plus as much supplementary information as may be secured. On the other hand, sometimes the child who presents problems may be seen in a residential setting from 2 to 10 days with a parent also present. Some authorities maintain that the child who is "difficult to evaluate" should be studied for a 6-month period, preferably on an inpatient basis, before any attempt at appraisal is made.

The examiner responsible for evaluating the blind child may feel inadequate if he is unfamiliar with some of the characteristic behavior and skills of a person functioning without sight, such as his use of auditory cues or methods of orientation in a new environment. Bauman has discussed some ways of working with the adult blind client which may be suggestive also for the person working with children.[1]

A complete history of the child's physical and emotional development during his first 5 years of life should be available to contribute to the evaluating process. If the child is entering an educational program, any report of early group experience, such as nursery school or kindergarten attendance, should add to the educator's understanding of the child's development. He will want to know, too, if the child has ever been hospitalized for any length of time, particularly in infancy when first relationships with people are generally formed. Moreover, such knowledge may be helpful in understanding the parents' feelings toward their baby.

Of special significance in planning for the child will be the ocular report indicating the cause of blindness, congenital or otherwise, and the length of time the child has had a visual loss. When interpreting the report one will note especially the age of the child at the onset of blindness and the amount of his visual acuity if there is light perception or more residual vision. Such information may help to explain why some of the child's concepts in certain areas may be weak.

According to studies of the development of children who are blind, behavior which in children with vision would seem to be symptomatic of mental deficiency, brain injury, or severe emotional disturbance must in a blind child be looked at not in relation to the development and functioning of the

Once regarded as having little educational potential, this blind child is now developing well under skilled guidance.

sighted individual, but in relation to its purposefulness or meaning to a person who is growing and functioning with little or no sight.[2]

For example, the examiner may be cognizant of the factors in the early life of the blind child which might have contributed to his passivity or autistic behavior, such as isolation in an incubator, the early attitudes of his parent toward his blindness, and evidences of emotional deprivation.[3] Or the examiner may note the motor activity of the child. Perhaps the child's stiff gait results from lack of early motor experiences. Perhaps his toeing outward and the slight stamp in his step may be part of his effort to get auditory cues for orientation purposes as he walks. The excellent memory of many blind children can be of real advantage to their functioning as blind persons and should not be regarded as a negative factor indicative of bizarre development.

The examiner will realize that some children refer to themselves in the third person because that is what they have always heard. He will also want to know how much life experience the child has had that could contribute to his development of a positive concept of self.[4]

As has already been indicated, the psychological instruments themselves are limited. At present the Interim Hayes Binet Tests for the Blind (1942 Revision) is the only standardized instrument for children who are blind.[5] Most psychologists agree that this test is not reliable for children under 6 and do not advise it for those over 12.

For the very young blind child the Maxfield-Buchholz Social Maturity Scale may be used. As the name implies, it is a measure of social maturity only. In using it the examiner is dependent upon the responses of the parent to questions concerning activities indicative of the child's development. The limitations of such a scale are obvious, as it is natural for parents to be anxious about their child's performance in relation to other children.

Blind children may also be examined with selected parts of certain standardized tests for sighted children, such as the Cattell Infancy Scale, the Wechsler Intelligence Scale for Children, and the Merrill-Palmer Scale. Again, many examiners will use selected portions of these instruments, depending upon the individual being evaluated.

Most blind children are able to cooperate with the psychologist during the tests, but those who present the most baffling problems sometimes do not respond in the normal test situation. Most evaluations, therefore, are the composite result of the observations and thinking of the psychologist, pediatrician, ophthalmologist, and social worker who know the child, supplemented by information furnished by the parents. Even with all this help, some children are singularly hard to evaluate for there is always the question as to whether one is dealing with true mental retardation or with a developmental retardation resulting from a multiplicity of factors, not the le of which is the traditional way of thinking about blindness.

Factors in Retardation

Many questions must be raised when a blind child exhibits signs of retardation. Does his retardation have a true biogenic basis? Is he slow to respond because he has been deprived, unwittingly, of learning experiences? Has his development been conditioned by the emotional climate in which he has been living? Has the sensory deficit, his blindness, contributed from infancy to the retardation by preventing him from using in the same way as a sighted person the neurological pathways ordinarily stimulated by vision.

For many years in the past blindness in a child was considered to be invariably accompanied by mental deficiency or with at least some degree of mental incapacity. Early literature indicates that the only care or attention given to blind persons was in institutions for the "mentally defective and the blind." Only in the last few decades have services been offered to blind persons on the basis of a consideration of their well-being. The realization by more than a few persons that the very young child who has severe visual loss may have excellent potentialities is even more recent. Even within the last decade parents of blind babies have frequently been told, "Your child is blind and perhaps the best thing to do is to put him away, forget about him, and have another baby."

Because more than 50 percent of the blind children born within the last two decades have a visual loss as a result of retrolental fibroplasia, a condition they acquired as premature babies, it has been easy to think of all blind children in terms of this diagnostic entity and, conversely, to think that the child who has retrolental fibroplasia exhibits characteristics common to all blind children. In consequence the adjective "retrolental" has for many people certain false connotations.

Studies by Hayes [5] have indicated no marked difference in the development of the child blind from retrolental fibroplasia and the development of children blind from other causes. Though oxygen has been found to be a significant factor in causing blindness in the premature eye, the studies of Krause and Patz [6, 7] have seemed to indicate that only the eye was damaged. No evidence was found of neurological injury. However, prematurity does have its hazards and the same child may be a victim of some of its complications as well as of blindness.

Information pertaining to the cerebral activity of children blind from infancy is meager. Gibbs found the electroencephalogram pattern in blind children to be similar to that of brain-injured children.[8] However, it should be noted that 33⅓ percent of the sampling used in his study was drawn from a school for mental defectives. One should also bear in mind the fact that neurologists are apt to see blind persons only when they are institutionalized or are patients who have come to their attention because of questions in regard to their neurological functioning.

Though some neurologists report a spiked pattern characteristic of impairment, there are also reports of blind children with bizarre behavior for whom the electroencephalograms show no significant abnormalities. Parmelee found that the electroencepholagrams on six children, blind from retrolental fibroplasia, were "not diagnostically significant, though two were suggestively abnormal." [9] A more extensive comparative study of blind children in an institution for the mentally retarded and in a residential school reveals "no neurological impairment due to factors responsible for retrolental fibroplasia." [10]

General Observations

A study of numerous case records of blind children, including health reports, developmental histories, and material descriptive of the environment in which the children have been growing has led to the following observations:

1. These children represent a variety of social and ethnic backgrounds. Many children come from homes of "average" or "above average" socioeconomic status.
2. When informed of the diagnosis of blindness parents have nearly always been told that the child has a poor prognosis not only regarding the possibilities of vision but also in terms of anticipated development.
3. In many instances the diagnosis of blindness was made after the child was some months old. The parents presumably delayed taking their child to the doctor in the hope that their fears of a visual loss were unwarranted, or that the child would be able to see as in growing older he overcame the handicap of his prematurity.
4. Mothers frequently express more difficulty than fathers in their feelings toward the child and his blindness; fathers often express a sense of inadequacy in knowing how to function with the child.
5. The child who is blind seems to be more emotionally vulnerable than other children and therefore to suffer more keenly when parents tend to be compulsive in their treatment or unable to give their warmth to the child. Parents may not be able to unbend toward the child because of their own feelings toward blindness.
6. There has generally been a multiple-discipline approach to the child's problems. In many instances children have attended one or more school programs and have been known to several social and health agencies.

Few blind children in the total population have such gross abnormalities as to need custodial care. However, the symptomatic behavior of the children under discussion is not always irreversible and should not be regarded as a basis for institutionalization. Parents can be so overwhelmed with grief and fear that they can offer little in the way of the one-to-one relationship needed by the very young child.[11]

Some blind children have resembled in appearance and behavior the emotionally deprived babies studied by René Spitz.[3] Moreover, they have responded effectively to management and treatment based on an understanding of their functioning in relation to their sensory deficit. As Norris has reported, the parents' initial attitudes toward the child and the existence and use of the appropriate community resources available to meet his needs will determine in large measure the "opportunities for learning" which the child will enjoy as well as his subsequent development.[2]

Appropriate Services

Perhaps the first steps in enabling a blind child to enjoy and benefit from an educational program must be directed toward helping his parents, for it is in the home in early life where the child normally develops trust, confidence, and belief in himself as a person. Accordingly, programs for blind children emphasize social casework service for the parents in an effort to give them a better understanding of blindness, of their own feelings toward their blind child, and of his developmental needs in relation to his visual loss. A second major focus of a program for blind children may be on helping the child himself to a better understanding of himself as a person. In some instances the child may need psychotherapy or "play therapy," carried out by a skilled technician familiar with the effects of blindness. However, the expense and in some areas the inaccessibility of such skilled help may make such treatment prohibitive for many families.

For the younger child a carefully selected nursery school may be recommended where the child can learn about himself as he is learning to respond to teaching techniques. Many blind children who exhibit bizarre behavior have never experienced the kind of close, warm, or continuing and satisfying relationship with adults provided in many nursery schools.

Many persons who have worked with children with atypical behavior, say that attention should be given to helping to build in the child a realization of personal worth rather than upon treating a particular symptom of emotional deprivation such as a lack of speech. However, speech therapy, per se, may be needed by some blind children who have articulatory problems or hearing defects.

Some of these blind children with behavior problems may have above average potentialities. Their keen sensitivity may be behind the severity of their reactions to the circumstances in which they have been growing. Such children may respond to learning experiences directed at broadening their knowledge of people, of the community, and of the world in which they are living without the great aid of sight.

Other children may be slower learners who require and respond to a slow approach with repetition and patience. But whether slow or bright the child needs some group experience and some individual help. The teacher, perhaps, must be part therapist—to know *when* to bring the child to a new experience—and part artist—to know *how* to provide this experience for him.

Many children upon reaching school age need an educational program provided on a residential basis, preferably in a location where the administrators may have available expert medical, social, and psychological services. Such a program allows the child to experience a change from the environment which may have been accentuating his problems, provides consistency of treatment, and permits opportunity for observation of his behavior by skilled professional persons on a continuum.

Every effort should be made to see that none of these blind children is overlooked, and that each receives the kind of individual attention that will permit and enable him to grow and develop to the maximum of his potentiality.

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